

## 'The ICECAP-SCM tells you more about what I'm going through'

Bailey, Cara; Kinghorn, Philip; Orlando, Rosana; Armour, Kathy; Perry, Rachel; Jones, Louise; Coast, Joanna

DOI:

[10.1177/0269216315624890](https://doi.org/10.1177/0269216315624890)

License:

Creative Commons: Attribution-NonCommercial (CC BY-NC)

*Document Version*

Publisher's PDF, also known as Version of record

*Citation for published version (Harvard):*

Bailey, C, Kinghorn, P, Orlando, R, Armour, K, Perry, R, Jones, L & Coast, J 2016, 'The ICECAP-SCM tells you more about what I'm going through': a think-aloud study measuring quality of life among patients receiving supportive and palliative care', *Palliative Medicine*, vol. 30, no. 7, pp. 642-652.  
<https://doi.org/10.1177/0269216315624890>

[Link to publication on Research at Birmingham portal](#)

### General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

### Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact [UBIRA@lists.bham.ac.uk](mailto:UBIRA@lists.bham.ac.uk) providing details and we will remove access to the work immediately and investigate.

# 'The ICECAP-SCM tells you more about what I'm going through': A think-aloud study measuring quality of life among patients receiving supportive and palliative care

Palliative Medicine  
2016, Vol. 30(7) 642–652  
© The Author(s) 2016



Reprints and permissions:  
sagepub.co.uk/journalsPermissions.nav  
DOI: 10.1177/0269216315624890  
pmj.sagepub.com



Cara Bailey<sup>1,2</sup>, Philip Kinghorn<sup>2</sup>, Rosanna Orlando<sup>3</sup>,  
Kathy Armour<sup>4</sup>, Rachel Perry<sup>4</sup>, Louise Jones<sup>5</sup> and Joanna Coast<sup>6</sup>

## Abstract

**Background:** The ICECAP-Supportive Care Measure is a self-complete questionnaire developed to aid economic evaluation of supportive care interventions.

**Aim:** To determine the feasibility of completing ICECAP-Supportive Care Measure alongside EQ-5D-5L and ICECAP-A (generic measures used in economic evaluation) among patients receiving hospice care, close persons and healthcare professionals.

**Design:** Participants were asked to 'think aloud' while completing ICECAP-Supportive Care Measure and two other generic measures used in economic evaluation, EQ-5D-5L and ICECAP-A, and then participate in a semi-structured interview. From verbatim transcripts, five raters identified the frequency of errors in comprehension, retrieval, judgement and response. Qualitative data were analysed using constant comparison.

**Setting/participants:** Eligible patients were identified from one UK hospice by a research nurse. Close persons and healthcare professionals were identified by the patient. In all, 72 semi-structured interviews were conducted with patients ( $n = 33$ ), close persons ( $n = 22$ ) and healthcare professionals ( $n = 17$ ).

**Results:** Patients and close persons reported that the ICECAP-Supportive Care Measure was most appropriate for measuring their quality of life. It appeared more meaningful, easier to complete and had fewest errors (3.9% among patients, 4.5% among close persons) compared to EQ-5D-5L (9.7% among patients, 5.5% among close persons). Healthcare professionals acknowledged the value of the ICECAP-Supportive Care Measure but had fewer errors in completing the EQ-5D-5L (3.5% versus 6.7%). They found it easier to complete because it focuses on observable health states.

**Conclusions:** The ICECAP-Supportive Care Measure is feasible to use and perceived as appropriate for evaluating palliative care interventions. Healthcare professionals with limited knowledge of the patient who act as proxy completers may find the measure difficult to complete.

## Keywords

Palliative care, economic evaluation, quality of life, measurement, end-of-life care, think aloud, hospice

<sup>1</sup>Nursing Institute of Clinical Sciences, University of Birmingham, Birmingham, UK

<sup>2</sup>Health Economics Unit, Institute of Applied Health Research, University of Birmingham, Birmingham, UK

<sup>3</sup>NIHR CLAHRC Wessex Methodological Hub, University of Southampton, Southampton, UK

<sup>4</sup>Marie Curie Hospice–West Midlands, West Midlands, UK

<sup>5</sup>Marie Curie Palliative Care Research Department, University College London (UCL), London, UK

<sup>6</sup>School of Social and Community Medicine, University of Bristol, Bristol, UK

## Corresponding author:

Joanna Coast, School of Social and Community Medicine, University of Bristol, Canynge Hall, 39 Whatley Road, Bristol BS8 2PS, UK.

Email: jo.coast@bristol.ac.uk

**What is already known about the topic?**

- Measuring the quality of life at the end of life is complex.
- Generic healthcare instruments currently used to measure the quality of life among patients receiving supportive and palliative care have been heavily criticised for lacking sensitivity to deteriorating healthcare states.
- The ICECAP-Supportive Care Measure is an instrument that measures capability and sense of well-being developed for use in evaluation of palliative and supportive care interventions.
- This is the first study that investigates the feasibility of using ICECAP-SCM in comparison to other measures used in economic evaluation (EQ-5D-5L and ICECAP-A) among patients receiving palliative care, their close persons and healthcare professionals working in the hospice.

**What this paper adds?**

- The study demonstrates that the ICECAP-SCM is a feasible tool to measure the quality of life among patients receiving supportive and palliative care; it assesses attributes that are important to people at the end of life, is easy to complete and carries less risk of error in completion than EQ-5D-5L and ICECAP-A.
- The ICECAP-SCM is also a feasible measure for close persons to complete in terms of appropriateness and knowledge required for accurate completion.
- The ICECAP-SCM can be difficult for some healthcare professionals who may have limited knowledge about the patient.

**Implications for practice, theory or policy**

- This article provides insight into the measurement of quality of life for those approaching death, those close to them and those involved in their care.
- The ICECAP-SCM captures the subtleties required to measure the quality of end-of-life care more appropriately for patients and people close to them and may be useful in evaluating future palliative care interventions.
- The ICECAP-SCM is offered to researchers internationally for future research studies to measure end-of-life care appropriately, more easily and with less risk of error.

**Introduction**

The review of end-of-life care strategies across the United Kingdom,<sup>1</sup> Australia<sup>2</sup> and Canada<sup>3</sup> along with the identification of palliative care needs across Europe<sup>4</sup> and the recent global mapping worldwide<sup>5</sup> have led to increased interest in end-of-life care research. Some of this research is concerned with the effectiveness and cost-effectiveness of interventions and raises the question of measurement. Since the implementation of the National End of Life Care Strategy in the United Kingdom,<sup>1</sup> there has been increased focus on providing better care at the end of life with independent hospices being major providers of that care. In the United Kingdom, hospices provide approximately 80% of adult inpatient beds, as well as day hospice services and care at home.<sup>6</sup>

Meaningful information on outcomes in supportive and palliative care is required and it has been recognised that self-reported outcomes are particularly valuable.<sup>7</sup> A range of generic preference-based measures have been developed to assess cost-effectiveness of interventions within healthcare,<sup>8</sup> of which the most commonly used is EQ-5D.<sup>9,10</sup> However, generic measures have been criticised for their sparse descriptive capacity.<sup>11–13</sup> Their tendency to focus exclusively on health is also perceived by many as inadequate for informing decision-making in advanced progressive illness and at the end of life.<sup>14–16</sup>

There are alternative measures for economic evaluation being developed based on Amartya Sen's capability approach<sup>17,18</sup> which encourage a broad evaluative space through a focus on what a person feels able to do and who they are able to be. These include measures which assess the ability of a person to achieve a good life<sup>19,20</sup> and achieve a good death.<sup>21</sup> We do not know, however, whether it is feasible or acceptable for people at the end of life to complete these instruments. While information from individuals themselves is important for credible and trustworthy evaluation in research, it may be difficult to ask patients to complete such measures directly either because of fears of causing distress or because of fluctuating capacity and the frequently changing condition of people who are extremely ill. It is therefore important to ascertain whether such measures can also be completed by potential proxies including both those close to the patient and health professionals.

The aim of this study was to understand how people at end of life complete measures that might be useful in economic evaluation of health interventions, explore any difficulties in completion and ascertain views about the different measures. This article reports the findings from the study focusing on the completion of three measures by

patients receiving hospice care, by family and friends close to the person at end of life ('close persons') and by health professionals. The three measures considered are EQ-5D-5L which assesses health status,<sup>10,22</sup> ICECAP-A which is a generic measure of capability well-being for adults<sup>19</sup> and ICECAP-Supportive Care Measure (SCM) which is a generic measure of capability in relation to end of life.<sup>21</sup>

## Methods

This was a 'think aloud' study<sup>23-25</sup> in combination with semi-structured interviews.<sup>26</sup> A think aloud study is a cognitive interview; the patient is asked to verbalise his or her thoughts while completing a task (here, completing the three outcome measures). The think aloud approach enables the evaluation of the meaning of individuals' answers and the degree to which individuals encounter problems in completing the measure as well as the nature of these completion problems. The research was conducted under the guidance of the Ethics Group for the EconEndLife research programme as part of an European Economic Research Council Grant and gained ethics approval from North Wales NHS Research Ethics Committee – West (ref: 12/WA/0076).

## Sampling and recruitment

The numbers used in think aloud studies are variable. Two previous think aloud studies of capability measures have been conducted, one with 20<sup>27</sup> and the other with 50 individuals.<sup>28</sup> In this study, we sampled to obtain sufficient numbers both to make sense of the scoring for the think aloud and to reach saturation<sup>26</sup> in the semi-structured element of the interview. It was anticipated that up to 35 patients, 20 health professional and 20 close person interviews would be required to achieve saturation.

Participants were recruited through a hospice from the community service, day hospice and inpatient settings. The hospice provided care in day hospice, inpatient and community services for people who were receiving specialist palliative care for any advanced progressive illness. It is based in a semi-urban location and the care it provides is typical of palliative care services nationally in the United Kingdom. Annually, it has 400 hospice inpatients, 475 patients under the community palliative care team and 120 patients within the hospice day centre. Patients were recruited purposively from each of these areas to enable the recruitment of people at different stages in their illnesses and at different levels of dependency.<sup>29-31</sup> Patients were identified by the research nurse at the hospice (R.P.) who assessed eligibility and made initial contact and introduced the study; if a person was interested in participating, full study information was then provided by the researcher (C.B., R.O. or P.K.). To enable all types of patients to

participate, the inclusion criteria were broad; patients had to be receiving care through the hospice for an advanced progressive illness, consent to participate and be able to communicate in the English language (as the questionnaire is at this stage only available in English). Patients consented to their own participation and were asked to nominate, and consent to the participation of, close persons and health professionals who they felt would know them well enough to be able to complete the measure on their behalf. These potential proxies were then approached and consented separately. In cases where potential participants lacked capacity, a personal consultee could be appointed to enable approaches to be made to close persons and/or health professionals. In practice, this was not required.

## Instruments investigated

**EQ-5D-5L.** The EQ-5D-5L is a measure of health status commonly used in economic evaluation.<sup>9</sup> The National Institute for Health and Care Excellence (NICE) recommend the use of EQ-5D to assess the benefits of health- and social care interventions<sup>32</sup> because it has been weighted according to the social preferences of the UK population. The five level version, EQ-5D-5L, has five attributes each with five levels ranging from no problem to extreme problems. The five attributes of mobility, self-care, usual activities, pain/discomfort and anxiety/depression are used to ask about the participant's health state 'today'.

**ICECAP-A.** The ICECAP-A is a relatively new measure of capability well-being,<sup>19,33</sup> which is starting to be used for economic evaluation and has recently been recommended by NICE as an option for evaluating the impact of social care interventions.<sup>34</sup> Participants are asked to rate aspects of quality of life 'at the moment' across five areas: stability (able to feel settled and secure), attachment (able to have love, friendship and support), autonomy (able to be independent), achievement (able to achieve and progress) and enjoyment (able to have enjoyment and pleasure). There are four response levels to each attribute ranging from 1 (no capability), through 2 (a little) and 3 (much), to 4 (full capability). Validity and reliability of the ICECAP-A in the general population have been established,<sup>35,36</sup> but it has not previously been used with those at end of life. The ICECAP-A is available to view at <http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/HE/ICECAP/ICECAP-A/index.aspx>

**ICECAP-SCM.** The ICECAP-SCM,<sup>21</sup> is a capability well-being instrument developed for use in evaluation of palliative and supportive care interventions. The focus of the measure is to assess whether individuals have the opportunity for a good death.<sup>21</sup> The instrument has seven attributes derived from qualitative data collected from those at various stages along the trajectory towards death. Participants are

asked to indicate their well-being 'at the moment' in terms of choice (being able to have a say), love (being able to be with people who care about you), freedom from physical suffering, freedom from emotional suffering, dignity (being able to maintain dignity and self-respect), support (able to have help and support) and preparation (having the opportunity to make preparations).<sup>21</sup> There are four response levels to each attribute ranging from no capability (1) through a little capability (2), some capability (3) to full capability, generally expressed as experiencing a lot of an attribute (4). The ICECAP-SCM is available to view at <http://www.birmingham.ac.uk/research/activity/mds/projects/HaPS/HE/ICECAP/Evaluation-of-End-of-Life-Care/ICECAP-SCM.aspx>

### Data collection

Interviews took place at the hospice or another place of the informant's choosing. Clearly, the subject of the interviews was a sensitive one, and efforts were made to ensure that patients were comfortable with the interviewer and that support was available during and after the interview from trained professionals. There were three interviewers (C.B., P.K. and R.O.). Interviewers were either experienced in dealing with patients (pharmacist, nurse) and/or had previous experience of conducting research interviews on sensitive topics. None had any prior contact with any participants. Interviews began with collection of basic socio-demographic information and a warm up exercise to practice the think aloud technique.<sup>37</sup> All three groups were then asked to complete the three questionnaires about the patient's health and well-being as perceived from the patient's perspective. Participants were asked to concurrently verbalise their thoughts during the completion of the measures, using the think aloud technique. If informants were silent for longer than 10 seconds, they were prompted to 'keep thinking aloud'. The order of questionnaires was randomly allocated except where it was anticipated the patient may not be able to complete all three. In this case, the ICECAP-SCM was presented first, given that exploration of this particular instrument was the primary aim of the research. Following completion of all the questionnaires, a semi-structured portion of the interview explored informants' views about the questionnaires and the process of completion, focusing on issues such as the clarity of instructions, the ease of answering, the sensitivity of the questions, interactions between the measures and the ability of the questionnaires to capture the person's health and quality of life. Informants were given the opportunity to stop the interview at any point and particular attention was paid by interviewers to whether the informant was distressed or fatigued.

### Data analysis

All interviews were digitally audio-recorded, fully transcribed and analysed in two ways. First, the segments of

the transcript relating to the completion of items on each of the questionnaires were separated by questionnaire and item. This was then presented to five independent raters (C.B., J.C., P.K., K.A. and L.J.) in conjunction with information about the scores given by the informants. Raters were asked to identify, in relation to each segment, whether (1) it was free of error OR (2) any one of four types of response problem was present – comprehension (understanding the question in the way that the researcher intended), retrieval (successfully retrieving the appropriate information to answer the question from long-term memory), judgement (correctly judging how the recalled information should be used to answer the question) and response (providing a valid response to the questionnaire)<sup>38</sup> OR (3) there was no error, but the informant had experienced 'struggle' in arriving at their response.<sup>28</sup> Examples of the different errors can be found in Appendix 1. Where three or more raters identified the same error, this was automatically coded as an error of that type. Where three or more raters identified an error but classified the error types differently, the error was discussed and consensus about the nature of the error was agreed among the research team. Where two raters identified an error, this was also discussed among the research team to ensure that errors were not being missed. Where errors were indicated by only one rater or where no raters indicated an error, this was classified as not an error without further discussion. Error rates are presented as percentages for comparability, given that ICECAP-SCM contains more items than the other two measures.

Constant comparative methods were used to analyse the interview data. Transcripts were read and re-read, and categories and sub-categories were developed to describe emerging themes.<sup>26</sup> NVivo 10 was used to organise and manage the data (C.B.). Associations, relationships and models were developed from the original nodes (C.B. and J.C.) and used to provide insight into the measure completion and cause of errors. Transcriptions were not returned to participants due to the unnecessary distress this may have caused, particularly if a patient's state had worsened considerably.

### Findings

Interviews were conducted between October 2012 and February 2014. Eighty-two eligible patients were approached to take part; of these, 33 agreed. Among the 49 who chose not to participate, 17 felt too unwell or fatigued, 14 felt it 'was not for them', 4 had recently participated in other studies and 1 did not want to be audio-recorded. Thirteen gave no reason. From the 33 consenting patients, 22 close person and 17 health professional interviews were generated. Consent rates for close persons and healthcare professionals are not meaningful to present as patients had frequently already obtained consent informally before

**Table 1.** Participant demographics.

Characteristic	Participants	
	n = 72	%
Patient group	33	
Age group (years)		
>49	0	0
50–59	4	12
60–69	9	27
70–79	10	30
>80	10	30
Gender		
Male	21	64
Female	12	36
Condition		
Cancer	31	94
Motor neurone disease	2	6
Recruitment location		
Hospice inpatient	11	33
Hospice day case	14	43
Community	8	24
Close person group	22	
Husband/wife/partner	15	68
Friend	3	14
Son/daughter	4	18
Healthcare professional group	17	
Nurses	7	41
Doctors	8	47
Allied healthcare professionals	2	12

identifying the relevant persons to the research team: any reported figures would therefore be artificially high and, indeed, almost no close persons or healthcare professionals subsequently refused a request for interview. Overall, there were 72 interviews available for analysis. At this point, analysis of the qualitative data suggested that saturation within themes was achieved and recruitment was stopped. Characteristics of individual patients, close persons and health professionals are given in Table 1. The length of the interviews varied between 20 and 45 min.

### Patient measure completion

All patients completed the ICECAP-SCM and in most cases also completed the ICECAP-A and EQ-5D. Error (including struggle) rates are given in Table 2. There were some errors on all measures although the type of errors differed across the three measures as shown in Table 3. The smallest percentage of errors was in completion of the ICECAP-SCM for which the absolute number of errors was also smaller, despite the larger number of attributes and the higher completion rate (9 compared with 16 for EQ-5D-5L and 12 for ICECAP-A). One attribute within ICECAP-SCM was entirely error free (Support); the attribute generating most

**Table 2.** Errors and percentage error rate by group.

	Errors by group (percentage error rate)			
	PT	CP	HCP	
ICECAP-SCM items:	9 (3.9%)	7 (4.5%)	8 (6.7%)	24
PT: 231				
CP: 154				
HCP: 119				
ICECAP-A items:	12 (7.3%)	6 (5.5%)	4 (4.7%)	22
PT: 165				
CP: 110				
HCP: 85				
EQ-5D-5L items:	16 (9.7%)	6 (5.5%)	3 (3.5%)	25
PT: 165				
CP: 110				
HCP: 85				
	37	19	15	71

PT: patient; CP: close person; HCP: healthcare professional; SCM: Supportive Care Measure.

errors was 'Preparation'. In addition to having four errors, the item Preparation also had two instances of non-completion. It seemed that the major problem with completing this item arose from the difficulty in discussing advance care and funeral planning with people who are close:

That's a difficult one, 'being prepared'. The financial affairs are in order. We haven't got the funeral planned, because my wife won't talk about it. She won't talk about how she'll manage with the money if she was left on her own. She don't want to know. (PT27)

This was also the attribute where there was the greatest distinction made by informants between their capability (what they are able to do) and their functioning (what they do or have done):

That's a difficult one. It's not really that I haven't had the opportunity; the opportunity's been there, it's just that I haven't done anything yet. (PT22)

I've thought about it, but I've never gone to do anything about it ... I don't know what to put there ... I'll have to go for that one ... (PT17)

The attributes of the ICECAP-SCM appeared to be understood by all participants and completion was found to be feasible within all groups, including those inpatients very near the end of life. The measure was perceived by patients as being able to accurately and appropriately record their quality of life and on the whole patients preferred it compared to the other measures:

It [ICECAP-SCM] seems like a better choice than the other two, because, it's more about me, what I'm really like. (PT26)

**Table 3.** Errors by type across all participant groups for ICECAP-SCM.

Error type	Choice	Love	Physical suffering	Emotional suffering	Dignity	Support	Preparation	Total
<b>Comprehension</b>								
PT	0	0	0	0	0	0	0	0
CP	0	0	2	0	0	0	0	2
HCP	0	0	0	0	0	0	0	0
<b>Retrieval</b>								
PT	0	0	0	0	0	0	0	0
CP	0	0	0	0	0	0	0	0
HCP	0	0	0	0	0	0	0	0
<b>Judgement</b>								
PT	0	0	0	0	0	0	1	1
CP	0	0	0	0	0	0	0	0
HCP	0	0	0	0	0	0	0	0
<b>Response</b>								
PT	1	1	1	0	2	0	1	6
CP	0	0	0	0	0	1	0	1
HCP	1	0	0	1	0	0	0	2
<b>Struggles</b>								
PT	0	0	0	1	0	0	1 <sup>a</sup>	2
CP	0	2	0	1	0	0	1 <sup>b</sup>	4
HCP	0	3	0	1 <sup>b</sup>	0	1	1 <sup>b</sup>	6
Total	1	1	1	1	2	0	3	9

SCM: Supportive Care Measure; PT: patient; CP: close person; HCP: healthcare professional.

<sup>a</sup>Missing – participant did not answer question, not recorded as an error.

<sup>b</sup>Error due to lack of information.

That [ICECAP-SCM] tells you more about what I'm going through. (PT27)

Those at the very end of life (those in the inpatient unit,  $n=14$ ) felt the ICECAP-SCM was most relevant to their situation, while those at earlier stages preferred the ICECAP-A; few appeared to express a preference for EQ-5D-5L as the most appropriate measure:

This questionnaire [ICECAP-SCM] is designed, I guess, for someone in a specific situation where they're, maybe, in the last run-in, they're in a hospice situation ... an in-patient and I'm not, so it may not be applicable to all. Well, it won't be. (PT06)

That [EQ-5D-5L] is for somebody who's not really, you know, in a bad way at all, isn't it? (PT09)

One aspect of both ICECAP-SCM and ICECAP-A that was seen as advantageous relative to EQ-5D-5L is that they ask about how a person is 'at the moment' rather than 'today'. Because of the highly fluctuating nature of patients' conditions, they found answering questions about 'today' quite difficult at times:

I'd best put 'moderate pain' because it comes in bouts, it isn't constant, my pain. (PT12: EQ-5D-5L)

Patients also expressed concern over the 'usual activities' on the EQ-5D-5L, asking for clarification about

whether usual activities related to what had been usual pre-diagnosis or what was usual now:

What do you mean by usual activities? Usual before I was diagnosed or usual compared with the last year? A very tricky question. (PT06: EQ-5D-5L)

### Close person completion

Completion of the measures among close persons was similar to that for patients. Fewest errors were found on the ICECAP-SCM and most errors were made in completion of the EQ-5D-5L (see Table 2). Close persons were more likely to view the ICECAP-SCM as the most appropriate of the measures in relation to their loved ones' quality of life.

Generally, perceptions of the ICECAP-SCM were positive, with it being described as 'open', 'more appropriate' 'timely' and 'most important':

I think those [questions on the ICECAP-SCM] those are important questions. (CP15)

It seems to have everything on it with care, being with people who care, physical suffering, emotional suffering, it's all those really. (CP27)

Some close persons found completion of ICECAP-SCM more upsetting than that of EQ-5D-5L as they

reflected on how their loved one had changed over the period of their illness:

One or two were, but not difficult, it's an emotional time ... it reminds me when you are asked, 'Are they unable to do anything for themselves?' for argument's sake. ... it spells it out more clearly to you that it's happened, it's happening, and it's never going to change now. (CP05)

Others felt that some ICECAP-A questions appeared 'inappropriate' and 'insensitive' for people within the hospice setting:

I think the, that last one there [ICECAP-A], would be the least appropriate for me ... where he's in a hospice. He's completely reliant on other people. He can't do any of the things that would have given him pleasure and such like ... those things don't relate to him in the same way as they might relate to us. (CP34)

As with patients, the timeframe for EQ-5D-5L was perceived as problematic because of the rapid fluctuation of symptoms such as pain and nausea:

Well at the moment he's between two things really, one minute he'll be quite positive, and then another time he can be really depressed. (CP26)

It was clear that the accuracy and ease with which the scale could be completed depended on the relationship of the 'close person' to the patient:

He keeps it very close to his chest about his emotions, and I don't get it very often. So when I get it he is really very down, and that only happens when he's in pain. (CP06)

Unsurprisingly, given the patient findings, the ICECAP-SCM preparation question, which focuses on being prepared, financial affairs and funeral plans, was perceived as problematic for some close persons. Nevertheless, only one error resulted here, from lack of information:

She doesn't talk about funerals. She doesn't talk about anything in that department, and I would not, as a friend, go into that. I know [patient name] is okay. I should imagine if I'm sitting here, [patient name] would say to me, 'I've got it sorted', but she wouldn't go into details with me. (CP08 – friend)

I had to struggle with some of them because I'm not, I'm not close enough to him. (CP10 – neighbour)

Other close persons, especially spouses, were more confident in answering:

The opportunity is there and it always will be within the family and friends for anything that he wishes ... he likes the way down south in America they have the funeral with the

jazz band .... On the recording you can't see that I'm smiling, but we were only discussing it yesterday afternoon in the garden. (CP09 – wife)

### Health professional completion

While all health professionals were nominated by the patient on the basis that they knew them, it was apparent that some had more in-depth knowledge of their patient than others. This made answering some questions difficult for some health professionals, especially questions on the ICECAP-SCM that were perceived as more 'subjective':

They [on the ICECAP-SCM] were a bit more subjective, I think that's the right word, you know, feelings and pleasure. (HP34 – medical doctor, core trainee)

I think in this clinic area, we're a little bit more focused on the task and the treatment that we're providing. Even though we do look outside of that, we have to stay in a certain structure, I suppose. So that's [ICECAP-SCM] quite hard to – to answer some of those. (HP07 – hospice consultant)

This was in contrast to EQ-5D-5L, where health professionals who only saw patients less frequently at clinic or day hospice were more confident in their response:

The EQ-5D is more straightforward to answer because it's more like mobility, self-care, usual activity and pain discomfort, where it was more straightforward. (HP04 – day hospice staff nurse)

Generally, the nurses ( $n=7$ ) and one experienced healthcare assistant who participated tended to have a more holistic view of the patient and were able to answer quite confidently and without errors or struggle. Doctors ( $n=8$ ) completing the measure tended to focus more on managing symptoms:

It's knowing her better, maybe having seen her in a different environment, I think it makes a difference. I've seen her in her environment, it's a lot more personal. (HP08 – community clinical nurse specialist)

The one social worker who completed the measure focused largely on the patient's social care.

Health professionals were aware that their knowledge of the patients was limited by their tending to see them at particular times and in different settings, such as when they attended day hospice or as an inpatient during a crisis:

It's not like I'm a wife or a husband or mother of somebody who you're with a lot of the time and you see their ups and downs. The fact that they're here (day hospice) often means they're feeling a bit better anyway. So I tend to see her when she's in a better mood. (HP04 – day hospice staff nurse)



Some of these things are perhaps things that we've never specifically discussed in our clinic. (H09 – hospice speciality doctor)

Health professionals were also aware that it was difficult to get to know some patients well, either because of their personality or because of the illness trajectory:

Whilst I know on the day-to-day basis what his issues are I haven't been able to find out exactly how he feels about life and his situation at the moment ... some people give more information than others. (HP10 – community Macmillan nurse)

Inevitably these influences on knowledge affected how well health professionals could answer questions, and some errors were made due to lack of knowledge:

I have to say that I don't know, having only just started to talk about those things with [patient name]. (HP08 – community clinical nurse specialist)

Despite difficulties in answering some ICECAP-SCM questions, health professionals felt that it contained appropriate attributes for assessing end of life:

I think it [ICECAP-SCM] would be good, because these are some things that we don't actually very often ask our patients ... I quite like those questions. (HP34 – hospice speciality doctor)

On the other hand, the EQ-5D-5L was felt to be restrictive and would result in a more negative view of quality of life than experienced by the patient:

It looks [at] what people can actually do, that is only a very small factor of quality of life. I see it as involving lots of other things. (HP34 – medical doctor, core trainee)

As with close persons, health professionals were concerned about some attributes of ICECAP-A in the context of end-of-life care, particularly in relation to the achievement attribute:

I think an awful lot of people see a series of losses that they don't really have time to adjust to as they go along, so it's a difficult one. (HP23 – hospice speciality doctor)

I don't like that question because the general trend is they are deteriorating anyway. They can't achieve and progress and that feels harsh to say. (HP13 – consultant)

Having had the experience of looking after many patients at different stages in their illness, health professionals also tended to place their patients on a trajectory, comparing them to others who experience better or worse quality of life:

I suppose I am seeing other patients that have or are able to do much less and enjoy much less. (HP34 – medical doctor, core trainee)

## Discussion

This article has examined the ability of patients at different stages on the trajectory towards death, those close to them and those caring for them, to complete three measures that could potentially be used in economic evaluation of care at the end of life. There were some errors in completion of all three instruments. Among patients, the ICECAP-SCM had the lowest proportion of errors, around half of that for ICECAP-A and around a third of that for EQ-5D-5L. There was little variation in error rates between the three measures for close persons, although that for ICECAP-SCM was marginally lower. In contrast, among health professionals, error rates were highest for ICECAP-SCM, with around twice as many errors as for EQ-5D-5L. This increase in errors among this group seemed to relate largely to the level of knowledge about a patient. This suggests that careful targeting of those health professionals who have the best knowledge of the patient is important if the measure is to be completed by this group.

This is the first study to consider error rates in completion of these three instruments in the end-of-life setting, the first to consider error rates in completion of ICECAP-SCM and the first to explore error rates in completion by proxies in this setting. There is therefore a limited literature with which to compare the findings obtained here. The only study that has compared self-completion of ICECAP-A and EQ-5D-5L using a similar method is that conducted among the general population by Al-Janabi et al.<sup>28</sup> Error rates found across the two studies were not dissimilar, with the patient error rate for ICECAP-A here of 7.3% being slightly lower than that in the general population (9.4%) and the error rate for EQ-5D-5L here of 9.7% being marginally higher than that for the general population (8.8%). This suggests that completion of these instruments in a population of patients at the end of life is no more prone to error than their completion among members of the general public.

The study has a number of strengths, but also some limitations. It comprehensively covers all those who might be asked to complete instruments about patient health and well-being at the end of life. The study was conducted using a rigorous process for error identification and the number of raters was higher than in other similar studies.<sup>27,28</sup> The inclusion of further discussion in the interview after the conduct of the think aloud exercise allowed issues of completion to be explored, and this has helped to provide interpretation around the feasibility of completion of these measures. There are, however, also limitations in the study. For the most severely ill patients, it was not always possible to collect information on all measures; for this group, the order of

measures was also not randomised and this may have resulted in lower error rates for ICECAP-SCM than the other measures in this group if error making is associated with fatigue. Given that this non-random allocation only occurred in three cases, it is unlikely to have had a major influence on the findings. A second limitation arises because patients were sampled at one site and only through the hospice setting, a place for end-of-life care that is more associated with some trajectories towards death than others. The majority of patients in this study had a cancer diagnosis. Patients experiencing sudden death, for example, are very unlikely to be cared for in a hospice setting, and, currently, this is also the case for those experiencing trajectories associated with organ failure or a lengthy decline into frailty. Further work is in progress to explore the feasibility of completion among these groups. A third limitation is that all participants recruited to the study identified their ethnicity as white-British. Research into the feasibility of ICECAP-SCM among other ethnic groups would be valuable.

Despite the limitations, this work suggests that each of these measures can be completed with a relatively low number of errors by both patients and their potential proxies. Given this, the question as to which of these measures to use in empirical studies may relate more to which measures are found by patients to relate appropriately to their situation, which are found to be sensitive to change and, importantly, the normative framework within which the economic evaluation is being conducted. This article offers some suggestion that the ICECAP-SCM was seen positively by patients and those caring for them; as yet, however, there is no information as to construct validity, reliability and sensitivity to change, and further research is needed in this area. Nevertheless, for those conducting economic evaluation within a capability framework in which the purpose of end-of-life care is seen as being to provide the opportunity for a good death, this measure offers a potential way forward, particularly for those near the very end of life. Similarly, for those working within a health maximisation framework, the EQ-5D-5L has relatively few errors, particularly when completed by a proxy; the instrument was, however, less favoured by patients.

Overall, this article provides helpful evidence that it is feasible to use these measures with a patient population at the end of life, and that patients find the ICECAP-SCM, particularly, to be appropriate to their setting and context.

### Acknowledgements

We would like to thank Marie Curie Hospice, West Midlands, for facilitating the work and members of the EconEndLife advisory group and all research participants.

### Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article. JC was involved in the development of the ICECAP-A and ICECAP-SCM.

### Funding

This work was supported by the European Research Council [261098 ECONENDLIFE]. K.A., R.P. and L.P.s' posts are supported by Marie Curie. The authors would also like to thank Marie Curie for funding the open access publication cost.

### References

1. Department of Health (DH). *End of life care strategy: promoting high quality care for all adults at the end of life*. London: DH, 2008.
2. Commonwealth of Australia. The National Palliative Care Strategy: Supporting Australians to live well at the end of life, 2010, [https://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2FCA257BF000206168/\\$File/NationalPalliativeCareStrategy.pdf](https://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2FCA257BF000206168/$File/NationalPalliativeCareStrategy.pdf)
3. Health Canada (HC). *Canadian strategy on palliative and end-of-life care*. Ottawa, ON, Canada: HC, 2007.
4. Payne S and Radbruch L. White Paper on standards and norms for hospice and palliative care in Europe: part 1. *Eur J Palliat Care* 2009; 16(6): 278–289.
5. World Health Organisation (WHO). Global atlas of palliative care at the end of life, <http://www.who.int/nmh/publications/en/> (2014, accessed 10 February 2015).
6. Calanzani N, Higginson IJ, Gomes B. *Current and future needs for hospice care: an-evidence based report*. London: Help the Hospices, 2013.
7. Department of Health (DH). *Guidance on the routine collection of Patient Reported Outcome Measures (PROMs). For the NHS in England 2009/10*. London: Department of Health, [www.dh.gov.uk/dr\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_092625.pdf](http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_092625.pdf) (2008, accessed 10 February 2015).
8. Whitehead SJ and Ali S. Health outcomes in economic evaluation: the QALY and utilities. *Br Med Bull* 2010; 96: 5–21.
9. Brooks R. EuroQol: the current state of play. *Health Pol* 1996; 37: 53–72.
10. Herdman M, Gudex C, Lloyd A, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res* 2011; 20: 1727–1736.
11. Williams A. The measurement and valuation of health: a chronicle. Centre for Health Economics Discussion Paper 136, 1995, [www.york.ac.uk/che/pdf/DPI36.pdf](http://www.york.ac.uk/che/pdf/DPI36.pdf)
12. Dowie J. Decision validity should determine whether a generic or condition-specific HRQOL measure is used in health care decisions. *Health Econ* 2002; 11(1): 1–8.
13. Brazier J and Dixon S. The use of condition specific outcome measures in economic appraisal. *Health Econ* 2010; 4(4): 255–264.
14. Coast J. Strategies for the economic evaluation of end-of-life care: making a case for the capability approach. *Expert Rev Pharmacoecon Outcomes Res* 2014; 14(4): 473–482.
15. Higginson IJ, Evans CJ, Grande G, et al. Evaluating complex interventions in end of life care: the MORECare statement on good practice generated by a synthesis of transparent consultations and systematic reviews. *BMC Med* 2013; 11: 111.
16. Normand C. Setting priorities in and for end-of-life care: challenges to the application of economic evaluation. *Health Econ* 2012; 7(4): 431–439.

17. Sen A. *Inequality reexamined*. New York: Russell Sage Foundation, 1992, pp. 39–53.
18. Sen A. Health: perception versus observation. *BMJ* 2002; 324: 860–861.
19. Al-Janabi H, Flynn TN and Coast J. Development of a self-report measure of capability wellbeing for adults: the ICECAP-A. *Qual Life Res* 2012; 21: 167–176.
20. Coast J, Flynn TN, Natarajan L, et al. Valuing the ICECAP capability index for older people. *Soc Sci Med* 2008; 67: 874–882.
21. Sutton E and Coast J. Development of a supportive care measure for economic evaluation of end-of-life care, using qualitative methods. *Palliat Med* 2014; 28: 151–157.
22. Devlin N, Krabbe PM (2013) The development of new research methods for the valuation of EQ-5D-5L. *Eur J Health Econ* 14: 1–3.
23. Ericsson K and Simon H. Verbal reports as data. *Psychol Rev* 1980; 87: 215–251.
24. Ericsson K and Simon H. *Protocol analysis: verbal reports as data*. Cambridge, MA: MIT Press, 1993, pp. 228–242.
25. Willis GB. *Cognitive interviewing: a tool for improving questionnaire design*. Thousand Oaks, CA: SAGE, 2005.
26. Strauss A and Corbin J. *Basics of qualitative research. Grounded theory procedures and techniques*. London: SAGE, 1990, p. 149.
27. Horwood J, Sutton E and Coast J. Evaluating the face validity of the ICECAP-O capabilities measure: a ‘think aloud’ study with hip and knee arthroplasty patients. *Appl Res Qual Life* 2014; 9: 667–682.
28. Al-Janabi H, Keeley T, Mitchell P, et al. Can capabilities be self-reported? A think aloud study. *Soc Sci Med* 2013; 87: 116–122.
29. Lunney J, Lynn J and Hogan C. Profiles of older Medicare decedents. *J Am Geriatr Soc* 2002; 50: 1108–1112.
30. Lunney J, Lynn J, Foley DJ, et al. Patterns of functional decline at the end of life. *JAMA* 2003; 289: 2387–2392.
31. Murray SA, Kendall M, Boyd K, et al. Illness trajectories and palliative care. *BMJ* 2005; 330: 1007–1011.
32. National Institute for Health and Clinical Excellence (NICE). *Guide to the methods of technology appraisal*. London: NICE, 2008.
33. Flynn TN, Huynh E, Peters TJ, et al. Scoring the ICECAP-A capability instrument. Estimation of a UK general population tariff. *Health Econ* 2015; 24(3): 258–269.
34. National Institute for Health and Care Excellence. *The social care guidance manual*. London: National Institute for Health and Care Excellence, 2013.
35. Al-Janabi H, Peters TJ, Brazier J, et al. An investigation of the construct validity of the ICECAP-A capability measure. *Qual Life Res* 2013; 22: 1831–1840.
36. Al-Janabi H, Flynn TN, Peters TJ, et al. Test-retest reliability of capability measurement in the UK general population. *Health Econ* 2015; 24: 625–630.
37. Gilhooly K and Green C. Protocol analysis: theoretical background. In: Richardson J (ed.) *Handbook of qualitative research methods*. Leicester: BPS Books, 1996, pp. 43–45.
38. Tourangeau R, Rips L and Rasinski K. *The psychology of survey response*. New York: Cambridge University Press, 2000, p. 232.

## Appendix I. Types of errors.

	Error	Not error
<b>Comprehension</b> Any misunderstanding of a word, phrase or response option. Any words or phrase that the participant does not understand.	Being with people who care about you? I'm not sure what that means. I'm not with people all of the time [no box ticked].	Being with people who care about you? I assume it means when I want to, I am able to be with family and friends when I choose to [box ticked].
<b>Retrieval</b> A recall error or a miscalculation of the timeframe stated in the question.	Being prepared? I can't remember if anyone has ever asked me about making a will. I'll just tick some of the preparations. (NB: retrieval errors possible when patient has cognitive deterioration.)	Being prepared? It's not that I have not had the opportunity to plan a funeral but I would prefer not to think about it at the moment.
<b>Judgement</b> The participant's response does not match that of the investigators intent for the question item. Any recalled relevant experiences that the participant questions as irrelevant or inadequate.	Having a say? Well it's asking about how independent I can be isn't it? I cannot be independent at all because I cannot mobilise well without help.	Having a say? Well it's asking about how independent I can be at making decisions about my care and treatment.
<b>Response</b> Participant's desired response is missing from the written survey response choices.	Being with people who care about you? Yes, I've had great support from everyone [ticks never able to be with people who care about me].	Being with people who care about you? Yes, I've had great support from everyone [ticks most of the time].

(Continued)

**Appendix I.** (Continued)

	Error	Not error
Any response which is felt to be socially desirable answer. Participant's response is inconsistent with the personal experience expressed. Participant's answer is inconsistent with previous answers.	Physical suffering? Well, sometimes it is very bad and other days none at all but that option is missing <u>[no box ticked, or tick is in between two boxes]</u> .	Physical suffering? Well, sometimes it is very bad and other days none at all. I suppose sometimes is the closest. I'll tick sometimes <u>[ticks sometimes]</u> .
<b>Struggle</b> The participant has had difficulty answering the question, even when their final response is correct.	Emotional suffering? Sometimes, yes but I suppose I can't expect not to. I do feel like a burden, yes, erm which I don't want to but I suppose all old people do. So does that mean that I always experience emotional suffering? I don't know. I do worry about my children so what do I put? I sometimes experience it? I suppose I'd have to put that wouldn't I, sometimes [ticks sometimes].	Emotional suffering? Sometimes, yes but I suppose I can't expect not to. I'd have to put that wouldn't I, sometimes [ticks sometimes].